UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

THE TRANSFORMATION OF BIOLOGICAL RESEARCH AND SCIENCE IN NATIVE AMERICAN COMMUNITIES

A THESIS

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

Degree of

MASTER OF ARTS

By

NOAH COLLINS

Norman, Oklahoma

2019

THE TRANSFORMATION OF BIOLOGICAL RESEARCH AND SCIENCE IN NATIVE AMERICAN COMMUNITIES

A THESIS APPROVED FOR THE

DEPARTMENT OF ANTHROPOLOGY

BY

Dr. Paul Spicer, Chair

Dr. Kimberly Marshall

Dr. Heather Shotton

Dr. Elyse Singer

Abstract:

Native Americans suffer from drastically higher rates of health disparities than other minorities and have been the subjects of research and colonial classifications for decades. Because of a variety of factors have acted to establish and then maintain systems that essentialize Native Americans into a biologized fiction, such colonial science and scientific racism, Native people are hesitant to participate. This thesis acts to identify and then critique the unique ways that science and biological research are currently interacting with Native Americans. Subjects ranging from ethical, legal, and social implications to research methodologies and the future of genomics are discussed through a critical indigenous research paradigm. As there are very few Native people currently involved in these research forms and there are exponentially more techniques for conducting biological research; the need for analysis has never been higher. Although biological and social research have the potential to provide solutions for many problems, the ethicality of those solutions must be carefully developed with the input of community. Nation building recommendations for the future of research in Native communities as a whole are offered for those seeking to engage in research with Native people, or other at-risk minorities.

Keywords: Native, Native American, American Indian, Indigenous, Bioethics, Research, Genomics, Genetics, ELSI, Science, Perceptions, Health, Health Disparities, Biologization, Racialization, Precision Medicine, Biomedical, Sovereignty, CBPR, Community Based Participatory Research, Genetic Medicine, Capacity Building, Nation Building, Recommendations

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Native Americans across the United States suffer from a lack of access to health care, representation, and a variety of other factors leading to major health disparities (Sarche & Spicer 2008). Factors such as misreporting of Native American people from the Federal Government through the US census and private agencies and institutions lead to confusion about the real levels of health disparities and health outcomes among Native people. In part, this is due to the history of racism and stereotyping of indigenous peoples across North America as well as issues in categorizing Native people which in turn muddle identity formation. Native identity has become biologized, or made to seem biological, through United States policy and rhetoric. The result is that that health standards are affected to such a degree that Native people are less likely to seek medical attention for fear of being taken seriously and/or essentialized. The legal status of Native people and the legal history of interactions with researchers and US government agents have been markedly negative, leading to mistrust between governments and individuals. Tribes and tribal citizens have been and continue to be the subjects of unethical research at the hands of others and this in turn is affecting Next-Gen biomedical research, or genomics. Science has the possibility to alleviate Native health disparities and effect tangible change if applied through an ethical research methodology. However, it appears unlikely that these changes will take place without a transformation of scientific practice in Native American communities. Native researchers such as Katrina Claw and Nanibaa Garrison are stepping up to the plate to conduct research in their own communities and changing the perceptions of genomics research and science in general. As scientific techniques and discoveries are increasing exponentially, the need for trained Native bioethicists and scientists is growing. In order to keep pace with scientific advancements and improve the health of Native people, there must be widespread

transformation across Native North America to reshape ways that science is perceived, conducted. The goal of this thesis is not to establish a set of "best methods" for conducting research in Native American communities, but rather to suggest ethical alternatives for research in Native American communities. Among these suggestions are: the more Native people that are involved in research, the better the research will be and the closer research will come to ending the cycle of historic exploitation of Native peoples, new forms of engaging with tribes and with communities are essential for the continuation of research as whole, and the framing of social and biological research in Native communities must be considered on equal ground. All discussions throughout this thesis should be thought of in active context of representation, capacity/Nation building, and the distinct standards from non-homogenous tribes.

"BIOLOGICALLY" INDIGENOUS

There are many political and cultural nuances which can affect whether the demonym Native American is applicable to any given person, but in the field of genomics and general scientific thought the immediately relevant definition of Native American is a "biological" one (Act I, 2001). A full discussion of the politics of indigeneity and indigenous belonging in terms of citizenship is outside of the scope of this paper. More relevant for my purpose here, is the fact that how a person views themselves and their connection to indigeneity affects the ways in which they access healthcare which will be explained further in detail soon. Legally, in the United States, the terms "Native American" and "Indian" refer to Eskimos, Aleuts, and native North Americans (Wilkins and Lomawaima 2001). The US Census Bureau defines a Native American as "American Indian and Alaska Native." A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or

community attachment (Bureau 2010). The Canadian Constitution recognizes three groups of Aboriginal peoples: Indians (commonly called "First Nations"), Inuit, and Métis, but there is no legal definition for First Nations. In Mexico, the political definition in the 2nd article of the constitution is used to define indigenous peoples, whereas the census only reports on "cultural-ethnicity of indigenous communities that preserve their indigenous languages, traditions, beliefs and cultures" (Jung 2003). Self-identification and broad versus narrow definitions in the Mexican context can quickly change who is considered indigenous. While these are three very different means of classifying indigenous peoples across North America, the United States and Canada are unique in that they employ blood quantum systems to categorize Native people. As I demonstrate below, this system constitutes a pseudo-scientific method that integrates and conflates biology and culture.

In the field of indigenous identity construction, the use of biology to determine those included in a racial or a cultural category are taking on new forms through the incorporation of blood quantum, and DNA in the 19th and 20th centuries. "Biology" as a contributing factor to racial identity in Native American communities began after the Indian Removal Act was passed in 1829 (Thomas 2001: 43-113). The Indian Removal Act placed a blood quantum system on Native Americans by recording genealogy at the time of removal and then kept track of ancestral communities in the form of "Indian Blood" (Act, I 2001). In this system (saying that the first person recorded was full) blood quantum begins with a 1/1 "Full Blood Indian". If the child of this person was admixed with an individual who was 0/0 "Indian Blood" their child would be 1/2 "Indian Blood" and so on, dividing and multiplying where necessary. This blood quantum system was an entirely new colonial system of tracking Native Americans, initiated to eliminate Native people in enough time (Josiah 1833). This is not to say that no tribe in the United States

was using direct lineal descent to determine in-group and out-group identity, but the application is very different both in terms of kinship determination and in flexibility of identity. Blood quantum, as a system that only divides, places a finite number of generations at which point a quantum cannot be met and a person is no longer considered eligible for citizenship based on tribal constitution and federal guidelines. However, direct descendance is something that cannot be revoked and allows for lower blood quantum values while maintaining connection to tribes and ancestors.

Although the blood quantum system is still indirectly enforced by the federal government, there have been scientific advancements in the areas of understanding human genetic variation and genetic individuality. Two genetic systems are central to this discussion: nuclear DNA and mitochondrial DNA (henceforth nDNA and mtDNA). Nuclear DNA, the DNA that most people are familiar with, is acquired from both parents, and makes up the majority of an individual's genetic material. When speaking in terms of population demographics and genetic identity construction, nuclear DNA is used to identify percentages of relatedness to a community, from which the community is the sample being tested against, and the baseline is derived from those sample (Rodrigues 2008: 808-825). Depending on the scale and manner in which these DNA tests are conducted, an individual could have more or less percentage of relatedness to a group and *could* be considered Native American. The Cherokee Nation in Oklahoma often has individuals attempting to gain citizenship based on nDNA percentages of relatedness from genetic testing websites (Tallbear: 2013). They are told via popular ancestry websites such as ancestry.com, 23andme.com, and DNAconsultants.com that they have genetic lineages that are similar (to the sample sets) enough to be considered Native American, and some companies even offer specifically Cherokee tests (Cherokee DNA 2017). This is extremely

problematic in quite a few ways, but to only mention one, this percentage of relatedness is based completely on the sample size, and who is in that sample set (Bolnick 2007). What frequently happens is that the group who is being called Native American is self-identified and of negligible size (Koenig 2008: 234-249). More so, it is impossible to attach a specific tribe to DNA markers. Until the day on which we can 100% identify the complete variation between individuals it will continue to be impossible to do so. It is extremely difficult to speculate on the future of genetics and technology, but if that day does come, extreme caution and precision of language must be used by tribes who wish to elaborate on their citizenship based on biological traits. This specificity of membership has the potential to allow tribes to enact absolute sovereignty over who can be considered an insider. We need only look to World War II and the horrors of the Nazi party to see an extreme example of the negative results that can come from state-sponsored efforts to manipulate genetics, race, and population politics.

The next system is mitochondrial DNA (mtDNA). The most advantageous aspect of using mtDNA is the ability to infer ancestry via matrilines and therefore, population genetics. The use of matrilineal ancestry is also more applicable to understanding indigeneity because of how many Native American tribes trace their kinship through matrilineage rather than patrilineage. By reviewing mtDNA, the matrilineal ancestry of an individual can be inferred up to thirteen to fifteen thousand years ago (Goebel et al., 2008: 1497-1502) which is currently believed to be the period of initial occupation of North America by humans. Mitochondrial DNA can only be transferred from mother to children. Males are recipients and carry the mtDNA but cannot pass it on, and females have the ability to receive and pass on their mtDNA. Due to the differences in mtDNA, as opposed to nuclear DNA, (Jones 2004) those persons who are considered Native American in the United States who have an unbroken matrilineal line can be

placed into one of four/five haplogroups. These haplogroups--a group of genes that are inherited through a single parent and undergo selective pressures together--are A, B, C, D, and X (Schurr 2000: 246-253; (Eschelman 2003: 7-18). If a person in North America has one of these haplogroups, their matrilineal line is considered unbroken and is potentially traceable to one of these early dispersal matrilines in the Americas. Y-chromosome and nuclearDNA (nDNA) are also used in larger heredity testing projects, though they are used significantly less in tracing Native American identity establishing ancestral lineage. Moreover, the connection between the way that many North American tribes are culturally matrilineal, or trace their lineage through mothers, is an interesting aspect that is certainly being considered.

By saying if individuals have one of these five haplogroups they can be called Native American is also overly inclusionary. It should be known that there are individuals outside of the North American continent e.g. in Siberia and the Pacific Islands who have these haplogroups (Schurr 2000: 246-253). As a result, assigning indigenous identity to anyone found with one of these five haplogroups becomes problematic. As already mentioned, there are problems with identifying peoples' groups through generalized cultural terms, and the same is applicable when trying to apply biological systems to race. To give a historical example, common practice used to be measuring a human's skull in order to segregate different races of people (Gould 1996). Physical anthropologists would acquire human skulls, measure aspects such as facial angle and cranial capacity (Gould 1996). Those with facial angles that were determined to be closer to chimpanzees were determined to be savage and low intelligence, and through the collection of skulls from all over the world, this developed the idea of polygenism (Gould 1996). Polygenism is the idea that different races independently evolved all over the earth, and that humans are fundamentally and scientifically different (Gould 1996). These studies were disproved through

obvious errors in scientific understanding and the concept of race has since taken new groundings (Gould 1996). Contemporarily, race is understood to be social qualities and is constructed through shared cultural groupings and not determined by genetics (Allen & Jobson 2016). Race is also often demined by dominant authorities and the idea can be criticized for perpetuating hegemonic inequalities in society (Allen & Jobson 2016). Recent scholarship shows that factors such as academic education and age are significant in the conceptualization of race and its rejection or acceptance (Kaszycka et al. 2009). Race is socially constructed and there is no amount of biology that can completely define if an individual is socially/culturally an in-group member. In this thesis, I use the term "Native American" to address the peoples who are relevant to the topic of health disparities and genetic medicine. While I am cognizant of the murkiness entailed in using this term, I do so to avoid becoming overly specific and exclusionary.

In 1980, the United States Census began compiling data based on self-identified racial categories. The change from the 1970 census to the 1980 census, rather, represents an attempt to inflate and enumerate indigenous peoples. There was a 78.5% rise (or 635,290 people to equal a total population of 1,361,869) (Bureau U.C. 1790-1990) in Native American populations between these two censuses compared to a 44% increase (or 243,441 people) between 1960-1970 (Bureau U.C. (1790-1990). A comparable and notable change from the 1970 to 1980 census is the category of "Some other race," which jumps from 230,064 to 6,758,319, representing a 2,837.5% increase (Bureau U.C. 1790-1990). We can either understand that this was a particularly fertile period of time among Native peoples in American history, *or* we can infer that the United States Census Bureau has unreliable numbers for Native peoples. The Census Bureau's response to this growth when questioned was that these numbers were the "result of

natural increase and overall improvement in census procedures" (U.S. Census of Populations 1980, 1-2)! Prior to 1980, Native health care studies considered self-identification as sufficient so as to not complicate or skew data with identity politics (Sarche and Spicer 2008). Allowing for the United States government to define who is a member of a Native American tribe bolsters colonial power over Native lifeways and undermines tribal sovereignty. If the US government accepting forms of identification and association that tribes themselves have not agreed upon as requirements for that tribe, their sovereign right to determine the requirements for their citizens is undermined.

I argue for a change in convention away from relying on Federal data in health care studies. I propose relying instead on specific tribal clinics or Indian Health Services (hereafter IHS) facilities, which serve people based on tribal IDs, or political identity self-defined. This move would allow for individual tribal sovereignty and enable members to define who is or is not an insider (or citizen), while also removing the position of the researcher/agent in question's position as the voice of authority on an indigenous peoples group. The use of blood quantum to establish who should or should not be considered Native American perpetuates colonial systems of oppression and assimilation tactics. Some tribes choose to use blood quantum as a way to define their citizenship, and this is their right as sovereign nations, but the origin of blood quantum as a colonially imposed system cannot be overlooked. I would argue for a movement to indigenize tribal citizenship systems away from Federal or colonial ideologies in favor of tribally specific methods. The use of nuclear DNA or mtDNA is not useful in terms of determining who is or is not included as Native American and again distorts data. Studies on Native health care are not usually conducted in larger hospitals or health care facilities because the rarity of Native patients does not permit an adequate sample. Therefore, researchers must rely on tribal

governments, which have the most accurate idea of what constitutes a tribal member. Researchers often misinterpret identity or biological factors, resulting in a misguided use of the term "Native American." The standardization of "Native American" as an identity category leads to errors in data on health disparities. It is not the aim of this paper to establish a method for identifying who should and should not be considered Native American. Any mention of Native people throughout this paper should be assumed with a broad, encompassing definition.

UNIQUE LEGAL QUANDARIES & BIOLOGICAL OBJECTIVITY

Because of the unique legal and social status that Native Americans have in the United States, there are added levels of difficulty in engaging in social science research with these communities. In accordance with tribal sovereignty, each federally recognized tribe in the United States is viewed as an independent and (semi)autonomous nation. This means that grouping Native Americans into minority demographics is problematic for a number of reasons, including the ways this conflation elides the extreme differences within tribes. Federal-tribal interactions are meant to be government to government, and so one would expect there to be a paralleled level of authority over who is allowed to conduct research with tribes. For example, if tribes were considered true sovereign nations, consent forms would look significantly different. Consent forms would be tailored according to tribal policy and value systems, in the exact same way that there are differences between the US and China. Consent forms would more accurately represent the legislation and authority of individual tribes, which could potentially lead to more research interactions due to an understanding that beliefs and standards would be maintained. The researchers allowed into Native communities, the type of research being done, and the objectives of that research would also look significantly different than it currently does if

reflected by the approval process, of, say, China (Council for International Organizations of Medical Sciences 2002). Constant tampering with the legal status of Native people throughout the past hundred years has led Native Americans to have a social status akin to that of an endangered species. The pseudo sovereignty provided by haphazard congressional acts work to institutionalize the oppression of Native people (Wilkins & Lomawaima 2001 and Grande 2015). As Native people fall further victim to hegemonic structures such as institutionalized racism and oppression and social determinants of health created through those structures we are exotified and stereotyped (Remedios 2018). Social determinants of health include structural conditions that shape health outcomes, such as lack of transportation to health centers, social exclusion, unemployment, and lack of social support. These factors are created out of designed systems of oppressing groups of peoples. Systems of limitations that are avoidable and constrain the quality of life are forms of structural violence (Farmer 2006). Ideas of Native people such as beliefs about reservations as secluded havens are contradictions to real living conditions (Mihelich 2001).

There are also popular misconceptions about reservations as regions of the United States that are frozen in time--places where Native people live in a static, pre-contact cultural space (Leavitt 2015). Reservations and other regions with high Native populations are often the target for mission trips, political campaigning, and disaster porn (Salisbury 2017). Disaster porn is a term that has developed contemporarily as a way of describing the way in which depictions of extreme suffering and disasters are portrayed in the media (Recuber 2013). Popular media shows images of burning buildings, starving children, war, blood, and environmental extremes as forms of entertainment for the masses (Recuber 2013). Because there is a want to stay informed about the world by the public and to solicit an emotional or economical response by media institutions,

the misfortune of a others is crystalized into single shots or into epic blockbuster scenes (Recuber 2013). For Native peoples, media portrayal of lifestyles is often shown as static moments of suffering, such as in images from impoverished reservations (Leavitt et al. 2015). Beliefs from outsiders about traits of Native persons are largely based off of media and outdated history books (Leavitt et al. 2015). Through a lack of exposure there is a clear stereotyping of Native peoples from all people and even from politicians who are meant to understand their constituency and the demographics of the United States at a basic level. This is evident from observing the actions of politicians, such as the President of the United States, believe that using the name Pocahontas in a derogatory way implies a set of characteristics (Rushing & Edwards 2018). Pocahontas, otherwise known as Matoaka, was the daughter of Powhatan and a member of one of the first tribes encountered by colonizers. Hers is heavily stereotyped and sexualized in popular media, which directly contributes to sexual violence towards Native American women and is detrimental to the health of Native communities as whole (Marrubio 2006 and Ono 2001).

Modern American perceptions of Native people are based on a biologized view of indigeneity linked to myths of Cherokee grandmothers, high cheekbones, and blood /quantum (Denzin 2016). To my knowledge, there are no polls asking the general American public how they perceive Native people but based on information taught in American history curriculum (Sanchez 2007) there is much to substantiate this claim. Conflating biology and culture create strange research questions and questionable research objectives that leave biomedical misinformation in communities. This means that researchers/scientists communicate misinformation, and either never refute that information once more developments are made or are satisfied with their axioms. An example of this is the ‘thrifty gene hypothesis’, which will be explained in more detail later, which leads to Native understandings of diabetes acquisition and

health. Due to rampant racialization and biologization of Native Americans throughout society, studies must be vetted for the possibility of exotification as well as ethics. One such example is with the Western Mohegan of New York and wanting to use DNA tests to establish legitimacy as a political and cultural entity worthy of receiving federal recognition for a tribe (Tallbear 2003). This group attempted to use known associations of Y-chromosome and mitochondrial DNA haplogroups frequency within Native North Americans to then argue that they are Native American based on these shared haplogroups (Tallbear 2003). If this racialization was allowed, this group of people would have been treated as a Native American tribe and then whatever statements or conclusions made about that group through research would in turn be associated with Native Americans as a whiole.The oversight of research in tribes is then placed on the shoulders of the tribes themselves, who can lack the expertise, labor force, or willingness to engage fully with an uninformed populace. Not all tribes can be assumed to be large enough to dedicate a workforce to research studies. Though smaller tribes may have an interest in engaging with science, due to a lack of resources, they may choose to outsource oversight in order to obtain a better quality of interaction. A network of tribal interest groups, a consortium of tribal interest researchers, or groups with experience in conducting minority research and the unique aspects of tribal governance and interaction could be used to fill this need.

Bioethicists have noted that informed consent in biological or biomedical research with any population is complicated because of the extensive contextual information that is necessary for a participant to be truly “informed” (Manson & O’Neill 2007 and Beauchamp 2011). Sometimes, not even research assistants who are solicited to interact with the research subjects are aware of the study mechanisms they are administering. Due to the scope and growing collaboration of research consortiums, there is limited knowledge of the scope and/or further

intent of materials from one research project. Future intent meaning the use of data and or specimens in long-term contexts. Biomedical research projects can be so specialized that even the creation of a consent form is difficult because it cannot capture the nature of the research being done. If a participant signs a consent form to participate in a study but is not actually aware of what is going on, questions remain about the meaningfulness of the consent offered. Research is being conducted instead based upon an *acceptably* informed consent, where Institutional Review Boards (IRBs) determine what is and is not acceptable. The rise in tribally run IRBs has been beneficial in terms of alleviating some individual ethical grievances, but I believe that there is a larger issue with the lack of scientific explanation for any given study. IRBs, tribal or not, cannot be expected to be experts in all fields of study; there must be groups of culturally aware and technically trained individuals committed to upholding ethical standards of science. More so than reviewing every incoming proposal, these groups would be responsible for creating guidelines for fields that are becoming increasingly more specialized. The specifications of these groups are difficult to speculate, but several necessities would be: a wide range of fields of study covered, genuine cultural competency, multiple tribes and regions represented, experience in research, and knowledge of general Native American research history. These groups could function as consulting agencies requiring minimal fees, and not conducting research as that consortium. Although many of these are characteristics that I believe are necessary for researchers themselves, I do see a third-party consortium as essential for tribes that want to get another opinion on research that will potentially come into their community. There would not need to be very many of these groups, but much in the same way that IRBs oversee a large amount of research these groups could serve in the same capacity. As not all kinds of research

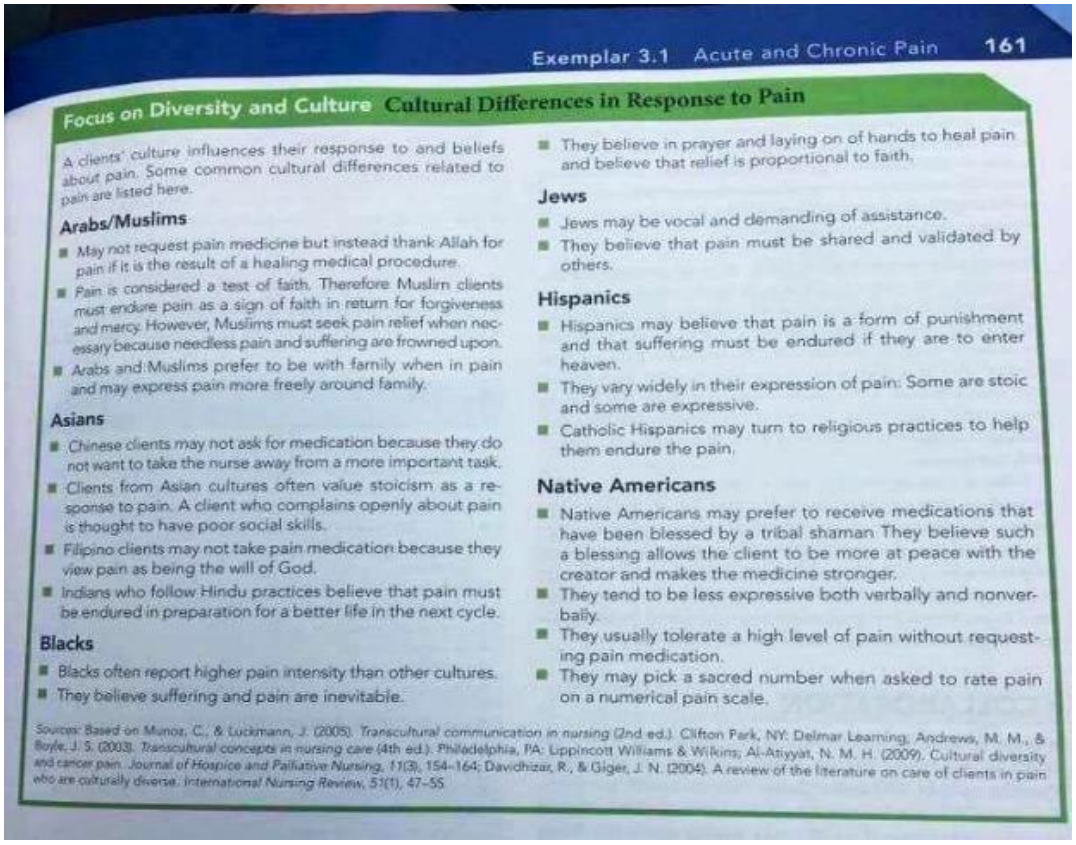
are even attempted to be conducted in Native communities, these groups could create a more efficient research process.

In light of high rates of poverty in Native American communities (Sarche and Spicer 2008), individuals may be overly incentivized to participate in a study for the compensation even when they do not fully understand study procedures. A number of anthropologists have argued that in ethical research, compensation for study participation should reflect local economic situations such that an individual does not agree to participate in a study based on a sum that is too good to turn down (Biruk 2017). Biruk (2017) for example, details a scenario for research compensation in Malawi where there is much debate surrounding what is considered a "non-coercive" compensation gift. There was sentiment by community members for "wages" to be received for time spent participating in a study as opposed to work, and as "gifts" in order to avoid inducement to participate (Biruk 2017). The community in Malawi wanted money, or a form of compensation that could be spent to reimburse their participation, but the problem for researchers was deciding what form of compensation was non-coercive. For a person living in extreme poverty with limited opportunities to make money or to provide for an extended family, as is the case for many Native Americans (Coontz 2016), even the "non-coercive" forms of compensation can be overly enticing. Even if a person carefully reads that a study participant has the ability to revoke consent, or that they have the ability to terminate their participation at any time, how is this person who has limited accessibility to necessities expected to actively follow a study that they participated in solely for the reward? The ubiquity of poverty among Native communities therefore raises serious ethical questions about how to address research compensation such that study participation is fully voluntary.

Another aspect of many Native tribes is the presence of deep relationships and involvement in each other's lives, which Wentzell (2017) calls "intercorporeality." This can be seen in the modern kinship and communal living styles of Native peoples. According to data from the 2010 United States Census, more than ¾ of the approximately 2.4 million population of Native American/Alaskan Natives live outside of tribal areas (Bureau). The majority of those who identify as Native American live in 10 states: California, Oklahoma, Arizona, Texas, New York, New Mexico, Washington, North Carolina, Florida, and Michigan (Bureau 2010). Urban areas across the United States tend to be more expensive than rural areas, except in cases of extreme distance from an urban center, which also tend to characterize Native American reservations (Bureau 2010 and Glaeser et al 2008). As seen through census information, Native peoples are living in large, extended family households, and the per capita demography of where Native people are found. Through research on mental health disparities in Native communities there is also evidence to suggest that those who have more communal lifestyles that they associate with a more "traditional" lifestyle have better mental health rates (Gone 2007). In this study Joe Gone goes on to develop community psychology insights for Native peoples that are heavily reliant on interdependency (2007). Intercorporeality in Native communities entails aspects of social responsibility such that individual consent can have larger ramifications for the entire community. Native individuals who opt to participate in a research study, in other words, may be offering uninformed consent for what they believe is best for their family unit or intercorporeal group. Legally, if that person decides to sign their consent to participate in the study they are agreeing to participate in whatever is written. In one case that shall be expanded upon soon, the case of Arizona State University, the Havasupai read and agreed to an initial

study, but due to the open-endedness of the consent form and the unintentionality of research (which will be expanded on shortly), there was a breach of trust and thus of ethics.

As an at-risk group, Native people are more likely to be the "subject" of research than active "participants." Research has proven that medical and biomedical personnel can have racist ideas that may be perpetuated in the name of cultural sensitivity training (Tucker 2002 and Williams & Mohammad 2013). One such instance is when a stereotype of Native people becomes integrated into healthcare and services outside of research. In an attempt to address cultural differences between health personnel and patients, nursing staff were trained to understand the pain responses of different minority communities. "Native Americans may prefer to receive medications that have been blessed by a tribal shaman" this 2015 nursing manual reads (See **Figure 1**). "They may pick a sacred number when asked to rate pain on a numerical scale" the graphic continues. Framing an indigenous person based on perceptions and stereotypes has been a major part of the biological and biomedical research industry, and actively shapes bioethical situations ways unique from other populations. This page exemplifies attempts at being culturally sensitive while enforcing scientific racism.



Exemplar 3.1 Acute and Chronic Pain 161

Focus on Diversity and Culture Cultural Differences in Response to Pain

A clients' culture influences their response to and beliefs about pain. Some common cultural differences related to pain are listed here.

Arabs/Muslims

- May not request pain medicine but instead thank Allah for pain if it is the result of a healing medical procedure.
- Pain is considered a test of faith. Therefore Muslim clients must endure pain as a sign of faith in return for forgiveness and mercy. However, Muslims must seek pain relief when necessary because needless pain and suffering are frowned upon.
- Arabs and Muslims prefer to be with family when in pain and may express pain more freely around family.

Asians

- Chinese clients may not ask for medication because they do not want to take the nurse away from a more important task.
- Clients from Asian cultures often value stoicism as a response to pain. A client who complains openly about pain is thought to have poor social skills.
- Filipino clients may not take pain medication because they view pain as being the will of God.
- Indians who follow Hindu practices believe that pain must be endured in preparation for a better life in the next cycle.

Blacks

- Blacks often report higher pain intensity than other cultures.
- They believe suffering and pain are inevitable.
- They believe in prayer and laying on of hands to heal pain and believe that relief is proportional to faith.

Jews

- Jews may be vocal and demanding of assistance.
- They believe that pain must be shared and validated by others.

Hispanics

- Hispanics may believe that pain is a form of punishment and that suffering must be endured if they are to enter heaven.
- They vary widely in their expression of pain: Some are stoic and some are expressive.
- Catholic Hispanics may turn to religious practices to help them endure the pain.

Native Americans

- Native Americans may prefer to receive medications that have been blessed by a tribal shaman. They believe such a blessing allows the client to be more at peace with the creator and makes the medicine stronger.
- They tend to be less expressive both verbally and nonverbally.
- They usually tolerate a high level of pain without requesting pain medication.
- They may pick a sacred number when asked to rate pain on a numerical pain scale.

Sources: Based on Munoz, C., & Luckmann, J. (2005). *Transcultural communication in nursing* (2nd ed.). Clifton Park, NY: Delmar Learning; Andrews, M. M., & Boyle, J. S. (2003). *Transcultural concepts in nursing care* (4th ed.). Philadelphia, PA: Lippincott Williams & Wilkins; Al-Atiyyat, N. M. H. (2009). Cultural diversity and cancer pain. *Journal of Hospice and Palliative Nursing, 11*(3), 154–164; Davidhizar, R., & Giger, J. N. (2004). A review of the literature on care of clients in pain who are culturally diverse. *International Nursing Review, 51*(1), 47–55.

FIGURE 1. Popular education publisher PEARSON's: *Nursing: A Concept-Based Approach to Learning, Volume I* page 161 from a 2015 publication on addressing diversity and culture.

BIOLOGICAL AND BIOMEDICAL RESEARCH

Many studies have been conducted in the name of the advancement of science and the betterment of society, but if one population has to suffer to obtain that goal, should it be done? Because of institutionalized racism and structures of oppression, in utilitarian research opportunities those that are sacrificed for the betterment of society are the typically those that are most vulnerable (Farmer 2003). Genetics research is so new and appealing, but the offer of

scientific and medical advancement comes at the risk of the human subjects that are being asked to participate. Native American communities are clearly receptive to the idea of genetic testing and the possibilities that come from the results as seen in participation in studies (Wang et al. 2007), yet this number overall remains low (Popejoy and Fullerton 2016). Tribes could greatly benefit from more research into health disparities. However, a lack of representation in terms of who is conducting the research and entrenched bias in what is being researched leads to issues such as scientific racism, absence of culturally appropriate techniques, and inadequate respect for persons. The benefits of having community representation in studies involved in that community, e.g. having a Cherokee community leader involved in the designing of a study in the Cherokee Nation are clear. Examples of these benefits include: new and more diverse research questions, identifying new limitations with existing scientific models and creating of new models, alternative hypothesis and interpretations of data, changing problematic and racist language, and better understanding risks (Intemann 2009). There is doubt, however, about the ability of one tribal member to be as effective in another tribal community, because tribes are, after all, non-homogenous.

The differences in local practice and beliefs makes it difficult to engage with multiple tribes based on familiarity with only one. Community based participatory research (CBPR) is gaining traction in Native American communities (Holkup et al. 2004). CBPR refers to a style of research that entails integration into a community to understand the local perceptions and beliefs, while also creating opportunities for collaboration on topics of interest to both researchers and communities themselves. CBPR involves community members in every step of research, including the generation of research questions, data collection and analysis, and culturally appropriate ways of disseminating findings. CBPR therefore reflects a political commitment to

democratizing the research process such that the entire research endeavor grows from the concerns and needs of the community under study and is poised to address and respond to those needs. A major area of contention among tribes is the dissemination of data that could damage the reputation of the tribe, or of individual Native Americans. In a famous study of ASU v Havasupai the error was with a breach of trust from using samples in a way that was previously not agreed upon or consented to, and for issues that the tribe does not discuss, such as migration and inbreeding. In another southwest example, well-respected biological anthropologists, archaeologists, and geneticists produced a publication in 2017 titled *Archaeogenomic evidence reveals prehistoric matrilineal dynasty (*Kennet et al., 2017). Without even getting into the substance of the article itself, there are major ethical lines being crossed in the title. Firstly, the use of the word "prehistoric" is part of unilinear evolutionist jargon where history, meaning events that have been recorded via writing systems, is the beginning of 'civilization' and anything before that is primitive. Secondly, using the word "dynasty" for Puebloan cultures or southwestern indigenous cultures is an imposition of western hierarchical structures. This article goes on to make claims about DNA extracted from "elite crypts" and examined for a "multigenerational matrilineal descendent group… demonstrate[ing] the persistence of an elite matriline for Chaco" (Kennet et al. 2017). There are major ethical concerns with the methodology of producing these results including objectifying word-choice, the use of descriptions that are not culturally sensitive, and the further marginalization of indigenous groups (Claw et al. 2017). Without even attempting to consult tribes for respectful ways of identifying and handling their ancestors, these scientists perpetuate non-Native control over "biological materials" and the alienation of tribes. Ancestors from Chaco were repeated referred to as "cranium 14," as objects, instead of once-living people and the relatives of living peoples.

Because only 0.05% of indigenous people currently participate in genomic research (Popejoy and Fullerton 2016), instances such as this work to further limit diversity and push Native people further from participation (Claw et al. 2017). Implications that arise from unthoughtful aspects of research can have particularly damaging effects on Native communities (Garrison 2017). A more cultural approach would be based on an understanding of historical biases and traumas, ongoing cultural problems, and relatability. All of these issues shape contemporary biological research in Native American communities.

There are likely as many forms of biological research as there are culturally distinct tribes in the United States. One category of biological research, and the focus of this discourse, is genomics. The exact definition of what constitutes genetics/genomics research can vary by institution, but for this paper, genetics research should be taken to mean any research conducted involving human DNA and genomes. There is also confusion over what constitutes worthwhile biological research as a whole, and especially worthwhile genetics research in the modern age. For some tribes, the apprehension with genetics research is twofold. On the one hand there is the risk of losing out on scientific gain because the opportunity to participate in research could easily be given to another tribe. On the other hand, if a tribe *does* participate, they risk being hoodwinked through unethical research practices and intentionally vague verbiage. For example, the Navajo Nation imposed a moratorium on genetics research in 2002, halting all genetics-based research concerning the samples obtained from citizens of the Navajo Nation (Reardon 2017). This moratorium acts to stop genetic research studies published within Navajo jurisdiction. Navajo Nation jurisdiction is ambiguous, especially when considering sovereignty and non-Native individuals. Data that is identified as Navajo is what is clearly within jurisdiction, meaning that deidentified, or genetic material labeled simply as “Native American,”

"southwestern," or "Athabaskan," etc. can be used despite the enacted moratorium. The goal was to keep the Navajo Nation from being taken advantage of through claims made about them or through their samples being used in ways that were against their wishes. However, they also lost out on 17 years of research and advancement (Reardon 2017). A significant portion of Native Americans that are currently publishing genetics articles and working as geneticists are Navajo (Claw et al. 2018 and Claw et al. 2017) but are unable to use their own genetic data for studies. This is not to say that genetics research is the end all, or even the most effective realm of biological research currently being pursued. Rather, I mean to say that there are significant scientific discoveries that are being pursued though genetics. To ignore genetics and the potential answers that can be provided simply *because* it is a trend would not be acting in a way that represents the adaptability and ability to accept alternative solutions that tribes have come to embody.

In the same way that Native people are unsure that outside researchers have their best interest in mind, Native people are unsure that they are receiving adequate healthcare and treatment. Indian Health Services, the product of Federal reorganization in 1955 of Welfare's Public Health Service (Lawrence 2000) is responsible for providing outpatient and inpatient service including dental, pharmacology, pediatrics, immunizations, and more (Zuckerman 2004). These services are available for citizens of federally recognized Native American tribes (with notable exceptions) in 12 area offices and 170 tribal/IHS co-managed service units across the entire country, equaling 1 IHS clinic per 9,805 square miles (adjusted for 47% inhabitation rates) (Busch-Geertsema 2010). The sparse distribution of Indian healthcare facilities leads to fewer Native people seeking health care and an increased difficulty in receiving health care (Garrison 2017). Even if healthcare is freely offered to Native people, if traveling to that healthcare facility

is strenuous and burdensome people will not be able to capitalize on this available healthcare. Travel to and from healthcare facilities is not free and given the scant distribution of facilities even routine procedures can prove overly demanding.

Because of the biologization of Native peoples, even Native people believe that the illnesses and health problems they suffer from are the result of biological facts and genetic determinants rather than social inequalities (Richards & Patterson 2006). Among Native Americans asked in a study conducted in the Southwestern United States, the idea of a 'thrifty gene' or a gene that was necessary for hunter-gatherer diets which then became the cause for health problems such as diabetes, gout, and hypertension after hunter-gatherer lifestyles were changed was prevalent (Richards 2006). Genetic fatalism shifts healthcare and indigenous views away from the social determinants of health and redirects attention and funds. For example, food desert research in both urban and rural settings confirms that diabetes rates are directly correlated with a lack of fresh produce, proximity to grocers, and reliability of electricity (Berkowitz et al. 2017 and Gordon et al. 2011). If a Native person believes that their health problems will occur regardless of lifestyle or accessibility to improved living conditions, they are less likely to use health services. Inability to access health facilities also perpetuates cycles of health disparities throughout generations. This is not to say that science and biology do not play an important role in the health of Native peoples, but attention is often shifted away from social determinants. Scientific understanding within Native communities is distorted through misinformation and lack of education, which are also correlated if not caused by overall perceptions of social status and infrastructure. This distortion can be lessened through multi-generational education and increased community involvement/engagement by researchers and scientists. Just because a technique like Next Generation Sequencing is new and expensive compared to other

technologies commonly found on reservations does not mean that scientific revolutions are unrealistic or unobtainable for tribal communities. Despite infrastructure or social barriers that exist in any given tribe or Native community there are outside partnerships, such as those available through the National Institute of Health and universities that act to make technological and scientific breakthroughs accessible.

The previous arguments have been framed in a biological versus social determinants of health framework but can also be thought of in terms of prevention versus treatment. While analyses of the social causes of disease can inform prevention, biological research on gene expression is often explicitly focused on treatment. Instead of looking at preventing diabetes from being acquired in the first place through healthy lifestyles, access to food, education on dieting, and increased infrastructure there is an overemphasis on the biological treatment of diabetes after it is acquired. In order to conduct a study to alleviate Native health disparities, a researcher must have funding to conduct their project. The biggest funder of domestic health research is the National Institute of Health, giving out more than $37.8 billion (Whitney accessed 2018). The National Institute of Health (NIH), based on grant funding history, is more interested in funding research based around discovering the mechanism for a particular disease and the prevalence of that disease in a population, or treatment, than the social determinants, or prevention (National Institute of Health 2 accessed 2018). This is not to say that social determinants of health research are not funded, but in the current state of health care and health care research social causes are often neglected for what is perceived as a more straightforward solution to health disparities. Instead of looking to eliminate unsuitable living conditions leading to harmful bacteria that make Native families sick, the NIH focus is on methods of treating the

family's sickness. This bias toward treatment of the biological cause of disease shapes not only health research, but also health care itself.

These biases are exacerbated in tribal communities. A report produced by the National Congress of American Indians found that Indian Health Services spent on average $2,849 per person versus the national average of $7,717 (Indian Health Services accessed 2018). Native people experience mortality disparity rates higher than any other race in the United States (Indian Health Services accessed 2018), while simultaneously receiving less health care and less preventive treatment than any other racial group. Comparatively, the 2016 Indian Health Service budget was set at $4.8 billion dollars (adjusted to $5.5 billion for FY 2018) for all American Indians and Alaska Natives, which translates to $1,297 per person, versus $6,973 per inmates in a federal prison (HHS.gov accessed 2019). None of this is to say that treatment is without value, or that prevention is 100% effective. However, there are clear priorities in government spending that aim to cure those who *may* contract a disease instead of preventing it in those who probably will. This reflects a continuation of historic government treatment of Native Americans (and other minorities) by not investing adequate resources into removing structures of oppression. By failing to adequately target the social determinants of health for Native people, such as lack of quality health care and education, the NIH and other institutions are unsuccessful. This is not to say that the NIH does not have programs targeted towards social determinants of health, but that these programs are failing to meet the needs of Native people sufficiently. Growing scientific discourse between prevention and treatment for health disparities are directly relevant to beliefs about the importance of biology versus social environments and biomedical research.

ROLE OF RESEARCHERS AND SCIENCE PROFESSIONALS

The role of researchers can often take on multiple forms, including training community members to engage with their own health disparities, when attempting to improve the health statuses of Native people. For many indigenous peoples, historic forms of healing and interacting have been turned into spectacle or called quackery (Wexler 2013). Native healing such as going to a medicine man, traditional plant use, and prayer, which used to be the immediate choice for many Native people, have been stigmatized by western science as illegitimate and useless (Struthers et al. 2005). As seen in the PEARSON nursing manual, Native interactions with medicine men are perceived as less legitimate than western forms. This colonial maneuvering has removed traditional methods of healing from being options for many communities, in this case meaning pre-tribal relocations. Contemporary portrayals of Native healing in mass media and literature, such as "New Age" spiritualists co-opting sweat lodge ceremonies, sage, peyote, etc. have distorted both insider and outsider views (Johnston 2002). Insiders of communities that participate in traditional healing methods can be swayed by assimilationist and colonial views of Native healing which deters them from engaging with traditional forms of medicine while simultaneously lacking access to western health-care. Outsiders view traditional medicines as novelties while not understanding the significance, historical process of loss of these systems, and cultural importance. Because indigenous people are not being seen as fit to take care of themselves or being removed from situations where there are traditional methods of healing, there is a growing importance being placed on Indian Health Services (IHS) and researchers. Improving health care, then falls into the hands of those who may not have spent much time with any one community. If a non-Native researcher is to be expected to support any Native community, they must know their abilities, as an outsider, and what the most important tasks or abilities they have. The three main roles that should be taken up by all researchers wishing to

engage with indigenous communities are: providing knowledge to outside members that there is a community-identified problem, allowing for insiders/communities to identify problems and focus efforts on improvement, and offering intervention facilities and resources to improve health.

If there is a high suicide rate, members of the community with that high rate are obviously not unaware that there is a high suicide rate in their community. People outside of the community, however, may have no idea that suicide rates are any different than in their own community, or have a skewed notion of the severity. Researchers can take an important step in this initial information stage through multiple methods. One method can be that researchers further investigate a health disparity in a Native community and then distribute information about that disparity (at the will of the governing body) to relevant parties. Another method can be that researchers provide continuous updates on the status of a health disparity to members of that community and to members of the surrounding communities in order to ensure all relevant parties are not misinformed. These are simple actions in terms of what a researcher does for a profession and can provide valuable aid to Native communities. If the only knowledge of a health disparity, youth suicide, for example, is occurring at alarming rates, then there can be no assistance or attention from anyone that is unaware of its occurrence. If there is no help from outside the community, and the people within that community have already reached their capacity to engage in preventative measures, there will be no progress in improving quality of life. Simply put, all researchers have an important role of distributing knowledge that they have gained for the betterment of those they have studied.

Secondly, through conducting research, researchers open up the possibility of collaborating on projects to remove bias and allow for communities to empower themselves by

solving their own dilemmas. Researchers have had a long history of coming into indigenous communities and viewing themselves as the only people capable of creating any long-lasting transformations. It is true that having an outside view can identify details that insiders may overlook, but in order to have true paradigm shifts the community themselves must support and understand the differences that researchers want to make. That is why identifying causes of health disparities or the given community's issues, and empowering communities to address areas of attention is critical to the success of any intervention tactics (Whitesell et al. 2017). In theory, a researcher has done the reading and enough work to be able to communicate aspects of surrounding information that community members may not have known were relevant or were having an impact on their area, such as in substance abuse scenarios (see Komro et al. 2015). If an indigenous community does not have trained researchers that are available to conduct studies for the interest of the people, this responsibility falls to the researcher that wants to conduct a study with those people. A major aspect of conducting ethical, useful, and unbiased research is through community based participatory research (Komro et al. 2015). Researchers of all kinds are in a position to help direct efforts to be more effective *for* the people. These efforts are capable of easily improving quality of life and health conditions of Native people simply through involving their subjects in their work. Although CBPR is beginning to be more widely spread throughout the research world, the idea of community incorporation and foundationalism is not new to indigenous communities, especially the one in which I was raised. I argue that other Native communities, similar to those that I am familiar with, have been incorporating the values and methods found in CBPR for thousands of years and are more suited to use in each individual community than CBPR. Furthermore, I argue that if scientists look into the cultural practices and

ingrained belief systems of tribes they will find that there is a methodology more comprehensive than CBPR, that is a more fitting research framework to use.

Thirdly, researchers providing in a word, resources, for indigenous communities is a serious role to undertake. Resources can take on a variety of forms, such as facilities, transportation, infrastructure, business, grants, publicity, medicine, or manpower. Nothing that can be considered a resource is necessarily easy to procure, or cheap, but for the indigenous communities that are often the focus of research these resources are hundreds of times more difficult to procure than they are for a researcher. If indigenous people do not have the physical ability to improve their environment, then any hopes of improving health conditions are impossible. When planning a course of study or deciding on an area, researchers need to take into consideration their ability to provide resources for the people in question. If there will be no benefit to the community aside from a publication, this is not worthwhile research. Researchers are in a unique position to provide hard-to-obtain resources for Native peoples that otherwise are forgotten. A simple example is providing cash or gift-card compensation for participation. These study compensations are often acquired through grant applications on the part of the researcher, but for indigenous peoples there can be extreme difficulties in even procuring a job. Resource in this context is defined loosely, because the needs and wants of Native communities vary. For intervention-based programs, just having the facilities or educational options to learn about problems, such as mental illness and depression, can be challenging to impossible. Researchers can provide these services either themselves, or through their affiliations with grants and universities to make a more holistic approach to community-based participant research. Health disparities such as diabetes and obesity can also be alleviated through education programs, more accessible food locations, or through teaching about healthy living and providing produce. The

option to use outside resources is an opportunity that is not often afforded to Native communities.

In the same line of thought, the use of Native American researchers is often thought of in ways that are ineffective for the goal in mind. The goal for using Native researchers is for that person to be able to relate science to their community, ethics of their community to outsiders and their science, and use established connections and values as bridge between communities. I make a distinction here between Native people who have these connections, community values, and tribal belief systems and are then trained in research methods versus those people who are Native but do not have strong connections to their tribal value systems or beliefs. I am not making a statement that one is more legitimately indigenous than another, or any judgement towards their indigeneity one way or another. However, the diversity and accurate representation of multiple tribal communities is what is wanted and if a Native person does not have that then their contributions are not having the desired impact. It is easier to train a person to conduct research and ethical science practices than to teach that person a lifetime of cultural connections and community. Once these individuals have been trained they can then establish or join existing research consortiums, laboratories, institutions, etc. and make necessary methodological and ideological changes.

PERCEPTIONS AND PROCEDURES OF BIORESEARCH IN SOCIETIES

Perceptions of genetics research and of biological research for Native communities are based in the past, present, and future. Stopping the continuation of research trauma and exploitation in science is crucial for moving forward with tribes. Just as the Havasupai Tribe has taboos on certain topics being discussed, other tribal nations are defining what is acceptable

practice according to their cultural beliefs. As general American citizens, there is little influence that any individual possesses that can sway the direction of biological research on the population. The United States as a whole is a Western society (Drucker 2012), which means that the majority of citizens, who are non-Native, are more generally in agreement with the procedures set by those who share their similar belief system. In this instance, this means thinking of peoples as individuals, as opposed to willful collectives. This poses a problem for the direction of genomic research because times that ethics or methodology are challenged are typically when they are being applied to smaller communities, e.g. at-risk populations and especially tribal communities. I assert that this occurs because there is not a genuine understanding of biosharing, bioresearch, or biobanking and interacting within Native American communities. Although there are no direct statistics for Native Americans and understanding these concepts, there have been a number of studies showing that white, college educated, and employed Americans do not adequately value or estimate participation in these kinds of studies (Klima et al. 2014 and Barr 2006). Saying that Native people, who are at major educational and socioeconomic disparities from even other minorities (Sarche and Spicer 2008) will more thoroughly understand or value research and participation is a risky claim. Education on these topics is obviously a serious issue, but this also brings into question the aspects of broad and dynamic/informed consent.

Broad consent and informed consent for biosharing and biobanking can be thought of in similar realms of ethical repercussions. When obtaining consent for a study, particularly in studies where genomic data is being collected, there is a necessary component of obtaining consent from the subjects concerning what will be done with their data and samples. In this process that has theoretically gone through an Institutional Review Board (IRB), the patient is informed about the purpose of the study, the methods, what will happen with their data should

they chose to participate, and how they will be compensated. After the samples have been collected and processed, the specimens are turned into data. The distinction here is that specimens are a non-renewable resource. They can be used a finite amount of times. Data, or metadata, is the information that is obtained *from* the analysis of those samples, e.g .the A,T,G, and Cs from a DNA collection study. In the process of informed consent, participants can be told that their biological DNA specimens will be returned or destroyed, which allows for certain people to feel more at ease that their information has a limited use, like a specimen (Steinsbekk et al. 2013). However, broad consent allows for the data that was obtained from those samples to be put into a biobank, or an assemblage of the data from up to tens of thousands of patients to be stored indefinitely (Hansson et al. 2006). Patients lose track of what is being done with their data because it is after the study parameters and the patient/subject assumes that the data has been either returned to their possession or has been destroyed, all the while their data and specimens are being distributed and sold to global conglomerates and biobanks (Petrini 2010).

If patients assume that their specimens have expired, either because they are not aware of the biobanking system or because they believe that the specimens would only be used during the duration of the study, there is a clear abuse of trust that can be directly attributed to federal guidelines. According to the general requirements for informed consent set by Federal regulation for the protection of human subjects most consent forms specify that data and samples can be used and kept indefinitely for indeterminate purposes ("Code of Federal Regulations"). As seen, regulations, federal or not, do not mean that the methodology is ethical or properly considering risks that come with advancing technology. Once a participant has agreed and signed the consent form and waiver, they have allowed for their private information to be used in a variety of ways, such as being sold to any number of companies (Evers 2012). Tribal nations, in distinction from

Native communities, are at risk when engaging with biobanks because of the way in which they could be essentialized or turned into a racialized biological category. Native communities should be taken to mean a group of Native people living together or in the same area, but not necessarily from the same tribe or families. A tribal nation, however, is more specific and is usually comprised of related individuals with defined political, ethnic or cultural boundaries. This distinction allows for those within nations to be more easily classified into bounded groups or reduced down to the essence of that specific tribe. More than simple cultural homogenization, a tribal nation is vulnerable to both racialization and commodification. When vulnerable populations (Aday 2002) participate in studies that are purposely left open-ended they are being taken advantage of, and this continues the historical cycle of unethical research. I believe research that is conducted unintentionally poorly should be considered unethical. Working with Native peoples should not be done whimsically or out of convenience. Taking advantage of a faulty systems or under-developed, non-specific regulations, such as the new common rule, is unethical. Just because a law exists does not mean that it is ethical. There are hundreds of examples of this, but to use an example from Native history, it was once legal in the United States to murder Native Americans (Lindsay 2012).

When at-risk populations are involved, broad consent studies quickly become ways to further mistreat groups of peoples in the name of science. Native American groups in particular are at risk of having biobanked genomic data commercialized for entertainment purposes, an idea that will be expanded on shortly. Even with built-in consent-revoking measures, where a patient has the ability to revoke their consent at any time, this can only occur if the patient knows what is happening to their data. With many of the data sales taking place well after the described duration of the study, patients have no reason to suspect that their information is even in use

anymore to warrant the revoke of consent, and on occasion have authorized this use (Drabiak-Syed 2010). Revoking consent means to contact a researcher after a study has been consented to and can mean several things, from outright removing their data from the study, or to simply not participate further. It is impossible to say that Native people as a whole do not want their data to be shared, but based off of the currently available examples, Native people are either not being informed adequately enough throughout a study or are being treated like a never-ending source of scientific data simply waiting to be exploited. Because of the way in which Native people are biologized, homogenized, and viewed as a bounded, single, racial category, the things that affect one tribe may affect them all. Possible solutions for these problems could include updating participants of publications made that included their data, re-consenting individuals for every additional use of data, and updates.

Conversely, dynamic consent agreements are more along the lines of what one would expect to find in good CBPR, where the patient knows exactly what will be done with data and has prolonged communication between participant and researcher (Stein 2013). As Native American nations and research institutions are looking to forge connections and establish new lines of partnership, an absolutely necessary step is increasing the intentionality of research. I define intentionality in a number of ways. Several of examples of increasing intentionality that is seldom seen in studies with indigenous people are: lack of long-term engagement, lack of reciprocity, lack of education of participants, lack of cultural competency efforts, and many more. To expand on each example mentioned, there is a definite lack of continued engagement with Native communities by researchers after they have finished a study. Renowned Native author Vine Deloria Jr. wrote a commonly referenced book *Custer Died for Your Sins: an Indian Manifesto* about this exact topic and calls this type of "helicopter research" detrimental to Native

peoples. Even in this book that was originally published in 1969, the problem of a researcher only engaging with a community long enough to collect their data and then leaving was prevalent. The defense for this abandonment on the part of the researcher is that maintained connection with a community is expensive, sometimes requires travel, and or that maintaining connection is time consuming. If a researcher in Native communities has not allocated funds for engaging with the community after the study has finished or has not made plans to keep in contact with relevant parties during the creation of the project there was error.

The level of intentionality necessary with Native communities is one that demands active participation and engagement, otherwise there has been no progress, even since 1969. A lack of reciprocity in research can also be seen through a lack of distributing study findings, and in the case of biological/biomedical research this includes both actionable and non-actionable findings (Crew et al. 2012). Reciprocity in this context means reporting findings (both preliminary and published) in a way that a community/individual can sufficiently understand without having undergone a decade of school or training. Admittedly, communicating complex information in a way that a non-specialist can understand can often be difficult, but human subjects research, and especially Native human subjects, should be difficult. This is also intentionality in that there should be an understanding that the researcher will need to disseminate their findings throughout the study. Even beyond the end of the initial publication or data collection, if findings that were reported change given a new insight into the field or subject then participants should be notified (Mayer et al. 2011). An example of this could be that initially a participant was told that their specific gene variant was non-actionable, or that participant was not at risk, but then a discovery after the time of the initial reporting means that their variant *is* actionable or are now at risk (Crews et al. 2012). Again, this requires that researcher be intentional in that they understand that

working with Native peoples or tribal communities is an ongoing relationship, and that they will be expected to maintain transparency and communication. Lack of education is an area that was touched upon earlier, speaking of a community member not understanding a study enough to make a genuinely informed decision. Framed through intentionality, a lack of education means that researchers and scientists have a responsibility to educate Native communities not only on the fundamentals of the science they are studying, but implications of that study. Going beyond "There are no risks associated with participating in this study" as is seen on many consent forms is educating a community on implications. It requires that scientists understand cultural norms and boundaries enough to be able to tell a specific community relevant implication associated with participation. Minimally this would mean explaining that other tribes may or may not have had issues with similar projects, or through working through the problematic history of research in Native communities (Deloria Jr 1969). Intentionality in research in Native communities goes beyond what many researchers plan for in their budgets or typically invest in time and communication. I argue that an increased intentionality is essential for improving research methodology and community participation with Native peoples. Genomic data acquisition, as it currently exists, displays unacceptable levels of cultural insensitivity and a lack of anticipation of scientific advancement through not incorporating ethical failsafes for participants. Technology is admittedly developing faster than could be forecasted accurately, but to not attempt to build in contingency clauses for these advancements shows a lack of forethought and intention to protect those involved in the study.

A theme in much of the literature concerning the ethics of broad consent, and working with vulnerable populations in mass genomic studies, is that the prospect of planning for the future is difficult (Stein & Terry 2013 and Aday 2002 and Evers, Forsberg, & Hansson 2012).

Technology is advancing at such an incredible rate that, within a decade, there are devices and techniques that may become obsolete. Take for instance a Dell computer bought in 1986; a computer with 6 MHz, a 20 MB hard drive, and a 12-inch screen was $2600, and in 1996 for $2699 one could buy a 166 MHz Pentium, 2.5 GB hard disk, 17-inch display, 128 bit local bus display adapter with 2MB of RAM, a mouse, Windows 95, and an 8 speed CD-ROM with Microsoft Office 95 Professional (Chambers 2004 & Schlender, Woods, and Wilton 1997). This example can be easily translated to biobanks for storing biological specimens collected from studies or any number of laboratory equipment. The technological advances made from 1996 to 2019 are almost unfathomable. In the world of rapid technological advance, machines have "planned obsolescence" and developers design current technology to have a much shorter lifespan (Fishman, Gandall, and Shy 1993 & Agrawal, Kavadias, and Toktay 2015). Why then is genomics research, that is so heavily contingent on the advancement of technology, being designed to have open-ended and indefinite use?

One could speculate on the exact reasonings for as long as the studies themselves stockpile data and find no answer. To touch on one possible cause, there is a hope that if data is kept long enough it will become relevant again, or there may be the secret to human advancement locked away in one sequencing conducted in the 90s. Hoarding data is not the way to accomplish obtain significant information in the world of genomics. As older studies are reviewed, the data is found to be wrong or is simply no longer relevant (Goldacre 2015). In one example, a deworming study conducted in Kenya, published in 2004, conducted on over 30,000 children was found to have been seriously wrong in a number of areas (Goldacre 2015). Some of the informational data had been entered wrong, leading to incorrect p values and changing the statistical relevance of certain data sets, 21% of the children had no age associated with them,

and nine other major issues (Goldacre 2015). What is more concerning of this reanalysis is that it was a randomized clinical trial set. Out of thousands of randomized clinical studies conducted, a recent study (Ebrahim et al. 2014) found that only 37 had been reanalyzed, and of those, only five had been reanalyzed by researchers that were not involved in the initial studies (Goldacre 2015). This is not to say this data should be freely shared and distributed, rather the regulation and review process for data sharing should be scrutinized and altered. For example, in the case of Native American data, tribal IRBs, or other bodies such as NGOs, Not for Profits, and designated scientific consortiums could appoint and request observers to monitor relevant datasets.

To round off the discussion on ethical uses of biobanking, the "right to know" is a growing topic as genomic sequencing techniques advance. With the increasing ability to sequence entire genomes combined with better ancestral health information, it is becoming possible to learn the risk of passing on potentially "negative" genetic traits. Parents are wanting to do whole genomic sequencing (WGS) of newborns, which would allow for the screening of rare and severe conditions that could be treated early, such as cystic fibrosis (Goldenberg 2014 and Berg, Khoury, & Evans 2011). The ability to know your child's genetic future is somewhat enticing, because it could allow for possible treatments, but could pose serious ethical problems if the screening revealed that your child has Huntington's disease, which is untreatable. It is hard to say if a child would want to know that they have an inevitable disease awaiting them in adulthood, or what that child would do with this knowledge. Some countries (Mao 1998), such as those in the Islamic world (Al Aqeel 2007) require couples to have premarital genetic screenings before they marry. In many Native American tribes, women are forbidden from even knowing the sex of their child before it is born, which puts major boundaries on whether those women would seek formal medical assistance during childbirth or marriage periods.

There is a pervasive idea within contemporary culture that bigger data leads to better results and there is a dedicated literature on big data in everything from investment to school education (Baker and Gourley 2014 & Daniel 2015). It is true that the prospect of conducting flawed research is serious, but even more serious is the prospect that this flawed research is also in violation of the cultural views and standards of the people being studied (Vavena et al. 2015). This is parallel to the Arizona State University and Havasupai case study in which not only were research protocols being broken, but community standards of the management of the body were not being followed. Indigenous peoples as a whole are constantly the subject of studies and commercial endeavors (Denzin 2016 & Fur 2016 & Grande 2015) which frame the entire community as merely the researched and not the researcher. When Native peoples do not have the ability to become divorced from oppressive narratives such as, "it is too hard to conduct research in Native communities" or "Native Americans do not want research conducted in their lands" hinder beneficial genomics research, and general biological research from being conducted. Although it may seem like a paradox, the situation that Native people are currently found clearly exists. Native communities make up a very small percentage of overall scientific research and are often ignored because of the difficulty in conducting research with Native peoples. However, when research is conducted with/on Native communities it is often exploitative or unethical. An additional aspect that is true of any community with a history of exploitation is that they do not want to be further exploited. Native people understand historical and ongoing negative interactions, especially in terms of who and how those interactions are contextualized. This does not mean that Native people do not want research. It means that Native people want the research to be done in a way that is respectful, ethical, and does not violate

cultural or legal standards. In the end, each tribe should access their capabilities and decide if large bio-sharing is in their best interest and will ultimately benefit indigenous people as a whole.

THE ROLE OF GENOMICS IN HEALTH DISPARITIES

Native communities have recently been the subject of genomic studies for things such as population genetics, human dispersal, and the human microbiome (Sankaranarayanan 2015 & Moreño-Estrada et al. 2014 & Posth 2014). Some of this research has been conducted with a great deal of collaboration, such as Dr. Sankaranarayanan with Oklahoma tribes and the pursuit of creation a fuller picture of gut microbiomes (2015). However, in CBPR, the community is asked what problems are relevant to them, where they would like to see research conducted and how studies should be focused. With Native peoples suffering from health disparities at hundreds of percent worse than all other racial populations in the Nation there is a great need for useful engagement. For example, one in five Native American children between pre-k and 12th grade will attempt suicide, and suicide is the second leading cause of death in Native Americans (Borowsky et al. 1999 & Horwitz 2014). Native people see a need for research to identify effective intervention practices and improve environmental conditions that lead to suicide and other health disparities (Page-Reeves et al. 2018). Health disparities are the differences in the levels of health care accessibility and standards between different populations, in this case Native Americans and other Americans (Frieden 2013). In an attempt to alleviate health disparities, there is thought that through the incorporation of genetic information or the accumulation of genomic data there can be medicines created to target Native-specific causes for disease (Khan 2013 & Khan 2011). Among claims that any one race has the genetic predisposition to have a health problem come the claims that it is dangerous to mate with someone who is of that

particular race (Duster 2013). If a gene is linked to Native Americans, or any other ethnic group, there is almost a plague-like association with that group like with western Africans and sickle cell trait (Acharya & Ross 2009). Those persons who carry the sickle cell trait (SCT) are viewed as dangerous mating partners and were shunned from social settings by those who were superstitious or those who did not understand the inheritance of SCT (Acharya & Ross 2009). It is possible for anyone to carry SCT, though the chance is higher in Western Africa, where the stigma remains (Kamble 2000). If this same stigma would occur with an entire race of people, say Native Americans, as opposed to a geographic area, e.g. Western Africa, the results could be catastrophic for health care and general scientific perceptions of that group.

In the search for a gene found only, or mostly, in populations there is a concrete example of what has been a racialization of medicine. In 2002, BiDil, a drug that is a combination of two generic drugs targeted towards heart failure became approved by the Food and Drug Administration (FDA) as a drug *for* African Americans (Khan 2013). African Americans have a much higher rate of heart failure than average Americans (Gottdiener et al. 2000), and NitroMed, the company that produced BiDil requested race-specific FDA approval based on their African American clinical data (Khan 2013). This is extremely problematic for several reasons, one being that race has absolutely no effect on the outcome of using BiDil, and those that were enrolled in the clinical BiDil trial were "self-identified" as African American (Khan 2013). Because of the FDA approving this drug as targeted towards a specific race, there is a message that certain health problems or disparities are due to a person's *genetic* background, and not their environment or lifestyle. This same approach is being taken in new genomic research and is essentializing health disparities to bad genetics, or a return to the idea of eugenics.

After BiDil became approved and the proverbial door was opened to a range of race-based medicines, the question has become, what role does, and can genetics and genomics play in health disparities or in medicine? Many Native health disparities have clear roots in settler colonialism and the oppression of minorities due to institutionalized racism such as alcoholism, suicide, and obesity (Herne et al. 2014 and Landen et al. 2014 and Cho et al. 2014). Suicide has been linked to historical trauma and intergenerational trauma as caused by occurrences such as residential schools and forced poverty conditions (Elias et al. 2012 and Costello et al. 2010). Neither residential school nor poverty can be said to be genetic, though they have direct consequences on the health of all people. Native Americans suffer from significantly higher rates of health disparities because of a mixture of environmental factors and are at risk for diseases and disorders at the same rate as other humans. Genetics does have the ability to improve scientific understanding of specific health conditions and disease acquisition, but to say that any one race or cultural group is genetically predisposition to certain health factors is racist. It is my firm belief, that though genetics and health disparities occupy some of the same academic territory, their uses in medicine and treatment are distinctly different.

GENETIC MEDICINE AND RACIALIZED MEDICINE

Genetic medicine is the diagnosis and treatment or hereditary disorders and diseases, where there is an emphasis on medical care (US National Library of Medicine 2015). Precision medicine is innovative in that it is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person" (US National Library of Medicine 2015). An example of precision medicine that is already being utilized are the examinations of specific molecular markers only found on specific

types of cancer (Kummar 2015). For example, normal colon cancers that have the surface protein KRAS are likely to respond to certain anti-EGFR antibody therapies (2006), and non-functional or absent proteins do not respond (Tan 2012). Another example of precision medicine currently in use is growing replacement bladders by isolating a patient's individual stem cells, growing them in cultures, and creating engineered tissues (Orabi 2013). Despite these already available precision medicines, the genome of the individual must be studied. As of 2009, 96% of all participants in genome-wide association studies (GWAS) were of European descent, leaving Native/indigenous peoples as less than 4% of all samples (Popejoy 2016). Even making up such a small percentage of overall research, there are instances, such as the Arizona State University incident that are questionable and improper. It is true that medicine in general can and does benefit Native people, but it does not consider the environment, lifestyle, or epigenetic causes of any given disease or disorder with the specificity and emphasis that precision medicine does. Common medicine often is used as an examination of symptoms, e.g. if a child has the flu, they will be told to wash their hands more frequently and given a vaccine. This method does not consider if the child has access to running water or has been moving frequently due to unsafe home environments and is being exposed to more bacteria. Common medical treatments are too non-specific in approach, but this is not to say that all attempts at utilizing precision medicine have been perfect. There are several cases of large-scale racialization of medicine leading to cases of active scientific racism in health care. One such example is incorporating racial phenotype into healthcare practice. The use of phenotype in diagnosis easily resonates the ideas of phrenology from the 1800s in which measurements were taken of skulls. Based on the shape of the head, an individual was said to be more or less likely of committing a crime, and that further, certain races are more inclined to commit those crimes. Although there was an attempt to

base this in neurology, the manner in which a scientific concept was applied directly contributed to the continuation of racist ideologies (Banks 1995: 387-403). An argument is sometimes made when speaking about the incorporation of phenotype in health that is based largely on the definition of the word "phenotype" (Robinson 2012: 777-780). The use in this example is for comparison to contemporary forms of scientific racism.

Modern-day equivalents of ideas such as phrenology not only continue a cycle of unscientific pursuit but make incorporating methods that would alleviate health disparities more difficult (Emery 2001: 1027-130). Large organizations and educators have good intentions with publications or at educating the public concerning cultural sensitivity but only increase the amount of problems when addressing disparities. This gross oversimplification of ignoring sociocultural factors for the assumption that race can be genetically defined.

No matter how good the intentions of the individual in question or the organization are, if the results create an atmosphere that negatively impacts the community, and in this case the health care of the community, they should be at a minimum reevaluated. The goal of precision medicine/genetic medicine is to make sure that patients receive "the right treatment at the right dose at the right time, with the minimum ill consequences and maximum efficacy" (Mirnezami 2012: 489-491). Literature on general genomic incorporation into precision medicine speaks to the possibilities of greatly reducing the number of people who suffer from physical and mental health issues, though an issue is of course the lifelines that environmental factors vastly outweigh genetic factors in the contribution to disease risk (Guttmacher 2010: 161; Jameson 2015: 612-614). In addition to issues that affect the larger community more directly (such as cancer), the literature speaks to the advancements that are being made in the genetic field which can be translated to the entire field of health care (National Research Council 2011: 277-280; Ashley

2015: 2119-2120). A constantly emphasized theme is the only way genetic medicine and precision medicine can be useful in reducing health disparities will not be through cultural competency (although this does play a part) but through the understanding of the genetics of an entire population (Collins 2015: 793-795; Betancourt et al. 2000: 181-217). This brings to light issues of defining populations that will no doubt take place over the next several years. Native populations are a distinct minority in the United States, but in order to research population genetics there must be an understanding of why research on Native populations specifically is significant (Emery 2001: 1027-1030; Insel 2014: 395-397). There is a need for research and a need to prove Native issues are equally relevant to those of other groups. Although Native peoples are frequently grouped together for federal purposes, modern Native American populations have very different views on biological research being conducted. Each tribe has the ability to define what is considered a risk to their nation, ethical boundaries, and whether to participate in health-related research (Harding 2012).

When large corporations and publishers make a statement that is problematic it not only undermines progress, but taints training processes and ruins conclusions. The same principal holds true when researchers undergo a peer review process and complete a publication process. This contribution of problematic literature is better understood through an anecdote. Imagine that there is a community of people that live in a remote desert, and the only way to get water is to drink from a pool that is known to be toxic every fourth time it is used. If it was possible, the community would never drink from the pool at all in favor of a completely non-toxic pool, but it is impossible to go to another pool, and in order to survive must drink from the pool. In this analogy the community are researchers, who must use the published literature at hand, but the available literature is the toxic pool. In an already limited database of articles and studies,

researchers must refer to known faulty studies because it is the only information being produced. There are so few articles written about health disparities that mention Native communities that to even begin conducting research is difficult. Although there is a literature on Native communities and health issues, the majority was produced either before the human genome was sequenced or is/was speculative in nature and fully incorporates racist ideologies (see Torrini et al. 1992; Mello 2010). Literature before the sequencing of the human genome is inaccurate in that it is not based on real genetic variation (Aronson and Rehm 2015). This entire genre of bioethics has a Native author who has dedicated the majority of her career to the bioethics of conducting Native American research and identifying who is Native American (TallBear 2008: 235). This bioethicist, Kim TallBear, is at the forefront of the push for freeing the academic record of its problematic past, and accurately incorporating genetic information for Native people so that there can be progress. By leveraging her existing connections, community ties, and knowledge of larger indigenous-colonial historical interactions TallBear has established herself as a strong voice in discussions of biological identity and Native Americans. Speaking as one of the few indigenous scholars actively being referenced in this discussion, TallBear is in an excellent position to argue against racialization and biologization of indigenous peoples. TallBear recognizes problems that have been brought up throughout this paper such as Native misconceptions and metaphor such as “it’s in our blood/DNA” and the ways in which incorrect scientific thought not only effects health but undermines indigenous sovereignty and political standing. TallBear is also a part of a consortium of indigenous scientists from around the world called SING (Summer Internship for Indigenous Peoples in Genomics) that are actively working together to transform science and research in indigenous communities for the better. Through writing numerous articles, rebuttals, hosting internships, and providing global indigenous

networking. SING hosts an annual internship for tribal members to become more represented and educated in genomics and the sciences in general. This consortium acts as an advisory board to combat issues such as racialized science towards indigenous peoples, unethical studies, damaging publications, and regulatory processes over data and genomic capacity. Consortiums such as SING are the next step of many towards transforming the ways Native communities address science and research.

CONCLUSION

Although there is a paucity of indigenous scientists and researchers, mobilization and vocalization by those involved in consortiums and community based-participatory research initiatives are leading the way into the future. As Native people are increasingly treated as a biological species and racialized through colonial science and medicine. Because of the unique and complex legal status that Native people have there are challenges to sovereignty. These challenges are coming from every day citizens all the way to the President of the United States. The way that researchers, institutions, and the general public interact with tribal members and the knowledge that those groups have of Native people is often determined by ethically precarious scenarios and questionable results. The systems put in place to guard against these types of scenarios, such as consent forms, tribal and non-tribal IRBs, and research review boards, are a thin layer of protection for indigenous people from larger systematic and institutional abuses. In order to maintain the limited sovereignty that tribes have, and work towards a more comprehensive and real sovereignty in which Native people have the ability to mandate, establish, and improve research and science in their communities, there must be increased community oversight and participation. Native researchers--who have a connection and

understanding of ethical, cultural, and historical contexts of specific and larger indigenous communities--are essential in this transformation. Native consortiums and scientists are the best tools to engage with community members and outsiders helping to reshape perceptions and establish priorities for each community. Without saying that the problems for every community are the same, or that there is a simple way to fix hundreds of years of negative colonial-indigenous interactions, I see the politics of science deeply rooted in the power structure of who is conducting research and what they are researching. Through sovereignty and ongoing governmental interactions Native people have unique legal statuses. This status increases the importance of the understanding from people who are conducting research, and the methodologies they incorporate. The exact mechanisms of indigeneity and construction of "self" of those calling themselves Native are not necessarily important to me as an individual, but tribal sovereignty and the non-homogenous nature of tribes dictates that each instance should be reexamined for the best possible candidate and researcher. This is to say that the delicate and complex construction of indigeneity definitely plays a role in Native community research, but that indigeneity specifically was beyond the scope of this paper.

Biological research and genomics research are important, and health disparities are definitely attributed to many biological causes. However, social determinants often play a larger role in the health and wellbeing of Native peoples. Lack of employment, lack of infrastructure, social exclusion and other social determinants of health are all being perpetuated through misconceptions of science. These misconceptions, such as genetic determinism and biologization of race, are affecting where resources are directed, and the methods included in health disparities alleviation. Social determinants of health are often overlooked in favor of biological causes that are not always existent, leading to a delay in treatment and a lack of prevention. As technology

and scientific understanding increase at exponential rates it is important that Native people not be left behind out of ignorance towards the importance of social *or* biological determinants. Social determinants are often times institutionalized, which means that they are harder to identify and then mobilise against. This is to say that research into why a Native community lacks access to fresh produce, for example, is not growing or evolving at the same rate that the biological cause for Native susceptibility to diabetes is. Biological sciences are important not only for a holistic approach to health, but to change the perceptions of Native people towards their own health and towards science in general. Native people are underserved and underrepresented in the sciences and that will not change unless action is taken. Research as a whole, as seen through a number of case studies needs to be more intentional and more interactive with both individuals and with tribes, giving active updates and looking to reconsent at any instance of change. Increasing intentionality can take place through a number of ways, such as through consent forms, educational workshops, and active community engagement throughout the entire duration that a dataset is being used.

I do not believe that establishing a sort of triage system for the negative impact consequences in Native communities is necessary. That is to say that I do not know if it is possible or useful to say that education is a more immediate or important problem than biological research. Both are necessary endeavors for Native peoples and communities to grow and become healthier. That being said, the best people to lead research initiatives of any kind are those that best understand the cultural, historical, and legal quandaries of Native people. There are inherent responsibilities that come with organizing, overseeing, and piloting research and communicating, especially within Native contexts. In the future there must be more Native researchers, more Native consortiums, more collaborations that emphasize and play off of unique tribal sovereignty

while, increased emphasis on cultural and ethical methodology, and community involvement. This future must also include eliminating misconceptions of racialized or biologized versions of science, acknowledgements of both social and biological determinants of health, and the procedures of research being reconceptualized to minimalize risk to participants especially in the future.

RECOMMENDATIONS

My recommendations for the future are many, and I will try and summarize them all as concisely as possible. In order to move forward with research of any kind in Native communities there must be a change in the way that Natives are perceived as biological entities. This means moving away from genetic association systems (like mtDNA and Y-chromosome), warped ideas of inheritance (like blood quantum), and colonial policies that establish dependency guidelines for tribes to implement on their own people. I argue that tribes should revert to tribally specific and culturally relevant ways of maintaining their citizenship. This is not an easy task, and with the legal and political quandaries that surround treaties and form the basis for many Native-based services, this will certainly take an entire reframing of the interactions between the Federal government and sovereign tribes. Race is not biological, and so it must stop being discussed as if it is, especially in contexts of Native Americans, genomics with Native Americans, or popular media. The way that Native people are conceptualized and portrayed in history and media must be changed to accurately represent the humanity and non-static nature of our Native cultures. This can be achieved by looking at history curriculum, language, and reporting on Native people by Native and non-Native audiences and calling out instances that portray Native people as static, as stereotyped, or as racialized caricatures. The next step in this process is for there to be

active discussion acknowledging the hegemonic structures that maintain oppressive systems and institutionalized violence. This can take place as simply as having conversations, but in the context of research this means that those wishing to engage with Native communities must show that they are educated on Native historical context. I do not think that some kind of litmus test for cultural competency would be sufficient, but I could envision a type of IRB (perhaps from a tribal IRB) requirement verifying or measuring the amount of specific community knowledge that a researcher has with the subject population.

In the same process as filtering who is allowed to conduct research on the researcher side, filtering who is participating in studies must also occur. As described in detail, intentionality in research during the planning process must become common place when wanting to conduct studies in Native communities, especially if those studies are genomic, biological, or biomedical in nature. Researchers must think about the community not only through the duration of the study, but long after the study has been completed. Research is a ceremony and a relationship with a tribe or community and it must be treated in that way. Planning budget, return trips, and interactions for after a study is done well before the study has begun should be the new standard. Changing consent forms to reflect this change in ideology and collaboration is a natural step. As a natural second step is conforming consent forms to the reflect the values of specific communities and tribes and recognizing tribal authority over the will of the researcher, and as an equal to the federal government; if not more important than federal guidelines. Another problem with research in communities is the complexity and tribes not knowing the implications or researchers not knowing how to accurately report implications and risks. I say this can be solved through the creation of consultant consortiums or tribal interest research groups. These multi-national, multi-field, multi-regional consortiums would have the ability to examine research

proposals and inform both researcher and tribe about recommendations for continuing or for proceeding in the most ethical and productive way possible. This requires researchers that understand communal living, Native ethics, and cultural norms while understanding what it means to be from a community. The difficulty for those who were not raised within a tribal community or were raised without a strong Native identity and connection is being able to accurately represent those who were/do. Thus, training Native people in research methods and in diverse fields while planning for the future of research and exponential growth of technology is essential. This training can be done in dozens of ways, such as supplemental grants, educating community members, or training community members while a study is taking place.

Native representation in all fields is extremely low, but even lower in STEM fields. For biological, biomedical, and genomic research this is even more clear. The need for more people trained in research in the ways just described is growing as the fields are growing, and ideally there could be representation from every tribe in aspects of biological and biomedical science research. Because this is almost certainly an impossibility, or a multi-generational goal minimally, bigger tribes or institutions with more infrastructure need to step up and ensure that Native representation occurs. As discussed, the amount of Native data in studies is an extremely small percentage, meaning that the implications for Native people are even less understood outside of Native communities. Tribes have the ability and right to determine what to do when it comes to being involved with research and often exercise their right to not participate in research (as seen with the Navajo Nation genetic moratorium). Implications and risks are always present when engaging in research. I would rather have tribes participate at the most minimal grade they are comfortable with, rather than miss out on decades of research, and so I would encourage each tribe to seek out those persons who have the ability to represent their tribal values and worries in

the best way possible. With a better methodology and research process, in the way that I am recommending, these risks would be minimized, and tribes could more freely engage in research.

As seen through ideas about genetic fatalism/determinism there are many reasons that these transformations in biological and biomedical sciences are needed for Native communities. I believe that the idea of social versus biological determinants of health and the importance of one placed over another are also inimical to Native peoples. By placing too much importance on the biological determinants of health researchers, community members, and the general public will obtain a skewed idea of what is causing health disparities. By overlooking the ways in which biological research can aid in alleviating health disparities when they do arise the same is true. My solution is to not try and establish a hierarchy between the two. Both must be acknowledged and studies, and currently there are great strides being made in the field of genomics whereas social determinants of health are much more ingrained in society. Because of this hegemony and institutionalized structure, the changes that can be made to alleviate social determinants are less obvious or require more large-scale effort. Focusing either one aspect of health without the other is not beneficial, and so the role of researchers must be clear in how they plan to engage with communities. Engaging communities in different ways than historically has been the case is probably my biggest argument throughout this entire thesis. By changing the way that researchers interact with the community there is a possibility of halting the way that scientific racism persists and is spread. All of these recommendations, from establishing consortiums, reassigning authority, acknowledgments, and community work are examples of more than capacity building for Native peoples. They are examples of Nation building. As sovereign nations tribes, more than just random collections of peoples from someone in the country, have the ability to truly change the way that others, like scientists and researchers, interact with them.

Sovereignty is one of the main distinguishing factors of Native peoples in the United States, and by implementing these recommendations we can begin to see a change in the way that tribes function as distinct governments with control over their intellectual, physical, and spiritual property.

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